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The impetus of the film has shifted since I started.

Sue Zalokar: *How so?*

C.G.: My emphasis with the film started to become more about talking about isolation in the disability community as a whole, but specifically the brain injury community – and looking at the idea of transformation.

There's a lot of rhetoric in the TBI world that your job after a TBI is to transform – to regain normalcy or regain your lost skills. A phrase you hear a lot: "the new you." I have come to believe that the more important transformation is on society's end.

For me, (the film) is more about providing a counter narrative to this very personal hero's journey. You know, "Golden boy lost it all in a tragic wreck and now triumphs over adversity." That's very, very, very common. I want to provide a counter narrative to that by shining the spotlight on (the fact that) we as a community are allowing people with brain injury to become isolated.

As a society, we refuse to talk about suicidality and mental illness and what happens when someone with a brain injury has no sense of community.

The title (of the film) initially meant: Don't stop yourself from expressing your creative drive. But it really, to me, has become more about letting (people with TBI) know they are coming into an ableist, inaccessible world, and people are going to try to stop them by telling them they can't accomplish anything anymore or by reducing them down to an inspiration. People with TBI don't have to engage with that.

S.Z.: *I want to talk about the isolation. It is a huge issue. You mentioned that in your own experience, you don't have a lot of the friends you had before your injury. That really sticks out to me. I have a friend with a TBI, and he is very odd and quirky. It is quite difficult to maintain our friendship.*

C.G.: I'm thrilled to talk about that. Everybody just wants to talk about healing. "Do some yoga, do some meditation, eat coconut oil, think only positive thoughts," and it's like, Blah! We need to talk about what's hard.

In terms of isolation, a lot of people with TBI and then especially if you have TBI and addiction or TBI and mental illness, anxiety – we're quirky in some ways that are challenging for some people to tolerate.

What happened to me and what happens to a lot of people is when people first start to interact with you and you have impairments in your communication and your energy level is really low, you do weird things like close your eyes a lot or cover your ears. The big fear (for non-disabled people) is that this person is going to be like this forever and they don't have the energy to deal with that.

So a lot of people get dumped early on, and then their impairments get better – not everyone, but a lot of people. Some of those things go away or they get muted or people can override those quirks.

A lot of it comes from the segregation that our society has always had around disability. Segregation is universal in this



Cheryl Green is onstage with Brandon Scarth, featured in the documentary "Who Am I to Stop It."

COURTESY IMAGE FROM VIDEO FOOTAGE BY PAULIUS KONTJEVAS

ONLINE

Storyminders:
storyminders.com

"Who Am I to Stop It":
whoamitostopit.com

country. And so people are not accustomed to dealing with people with communication impairment, mental illness or emotional disturbance.

I think we would have a more tolerant society if we didn't have so much segregation of disabled people into special ed (classrooms), special Olympics, segregated special proms, group homes. All of that makes it harder for non-disabled people to tolerate a shift in the way they do things to accommodate us. There is the belief that it's really our job to be more normal or act more normal.

S.Z.: *It's been almost six years since your bike wreck. It seems that you are pretty high on the spectrum in terms of things you are able to do and communicate. You're producing a film, for instance. Do you have any comments about the spectrum of traumatic brain injury?*

C.G.: There are a lot of myths surrounding brain injury and recovery and impairment. I have a degree in speech pathology. I have that high-level training in what this all is, but I also have my personal experience and I have dozens and dozens and maybe hundreds of people in my life with brain injuries. I can tell you from both the technical perspective and the personal perspective, you just don't know (what recovery will look like).

You can't make predictions about where someone will be in one year or 10 years, whether they'll go back to work or not. You just can't account for how the brain heals. It also has to do with access to resources. Can they get Life Flighted to a trauma center, or were they left to languish for a long time? It matters the kind of support that you have.

Also, if you are constantly surrounded by people who are saying you're faking it, you need to work harder, act normally – that can take a toll on your mental health, and that exacerbates brain injuries symptoms as well.

S.Z.: *I'm thinking of Tracy Morgan. He is a beloved comedian who was quirky and bizarre before his brain injury. He's pretty transparent about his current state of mind.*

C.G.: Tracy Morgan is an exciting person to me, in general. His recent sketch on Saturday Night Live, oh my gosh! It's so cute. It's not closed captioned, which I hate, so I transcribed it and I posted it on my Facebook page with a transcript that I made of it because it's just too funny to not have access to it.

I don't know Tracy Morgan. But I will say that some of the transparency is a neurological condition where you cannot inhibit what you want to say and you just say stuff regardless of whether you should be protecting your own privacy or not. There is always the possibility that his transparency comes from his inability to not be transparent.

Disinhibition is something I struggle with all of the time. I'm getting much better. I work really hard at it. But sometimes I blurt out something that I shouldn't have.

S.Z.: *I wonder, what are we, as a society, getting right?*

C.G.: As a society, if you are white and middle class or higher, you are going to have a lot of things in your favor.

If you have a supportive family and or friend network, people who can drive you to rehab or help you with rehab exercises afterward. Or sit and be a friendly, compassionate ear. If you have access to the Internet and you can go stream brain injury radio network, which is live-streaming radio show where you can access the TBI support network online forum, which is kind of like a combination of Facebook and support group for the TBI community. If you have access, then our society is doing right by you. Tracy Morgan is a rare example in that he is a black person with TBI that we know about.

I recently wrote to five speech therapists who I know in town and I asked where are the African-American people going for support? And where are they going for medical care? I don't see them. I got a mixed response. I find this to be incredibly troubling.

S.Z.: *Captioned films take more concentration for my brain. How does closed*

captioning help people with TBI?

C.G.: I love that question! I'm a professional closed captioner and an angry activist around closed captioning.

I email people all of the time who I do and don't know and I tell them to closed-caption their stuff. Every once in a while, someone responds and usually they say, "Oh, yeah. That's expensive."

We know that deaf people and who are hard of hearing can benefit from closed captions. It also supports other people. For people with TBI and also a lot of people on the autism spectrum, auditory processing is very difficult.

If there is anything that all people with brain injury have, it's slowed cognitive processing.

Trying to follow a storyline that is unfamiliar just by listening is too frickin' hard. It is so helpful to read and listen at the same time. It really supports your memory. It supports you being able to pay attention. It supports you not getting lost in what they're saying – especially if they are boring or they talk too fast.

S.Z.: *"Who Am I To Stop It" focuses on the combination of art and disability. What is the significance of this?*

C.G.: In terms of disability, there are a lot of cases where people are willing to engage in art made by disabled people in a way that they are not willing to engage with the person themselves.

"Who Am I To Stop It" is showing the art of each person, but also their art-making (process). It not only gives something for the community to connect with, but also the people who are making the art are also connecting more with themselves.

It's that moment when they aren't talking about self-doubt and internalized stigma.

When they are creating their art, they are people with agency and decision-making (skills) and creativity and drive. That is something that we don't see a lot of in brain injury media.

These are people who do things and make things and connect with themselves and with other people.